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ABSTRACT

This report describes the genesis, definition and use of the Personal Outcomes database, a database designed to assess whether programs and services are being effective in helping individuals with disabilities. The database is based on 25 outcome measures in seven domains, including: (1) identity, which is designed to provide a sense of how people express themselves as unique individuals; (2) autonomy, which measures control over physical environment, daily schedule, needs for privacy, and privileged and personal information; (3) affiliation, which assesses connections to other people; (4) attainment, which looks at how people define success in both personal and social terms; (5) safeguards, which measure compliance with health and safety codes; (6) rights, which measure fairness and support for individual rights; and (7) health and wellness, which include the outcomes of best possible health, freedom from abuse and neglect, and continuity and security. Findings are presented from data mining activities conducted by the National Center on Outcomes Research on 4 years of personal outcomes data including 1,851 interviews with individuals with disabilities in programs in 27 states. Results indicate the majority of the individuals with disabilities were living in supervised living arrangements. (CR)

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THE COUNCIL ON QUALITY AND LEADERSHIP IN SUPPORTS FOR PEOPLE WITH DISABILITIES PERSONAL OUTCOMES CHART BOOK

June, 1999

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INTRODUCTION

Why Outcomes?

Social legislation and societal change in the past 10 years has been marked by several competing forces or paradigms in the United States, especially for people with disabilities. Chief among them has been the paradigms known as "policy devolution" and "program accountability," and "disability research" and "independent living." We are interested in the intersection of both sets of paradigms as they relate to people with disabilities, in general, and specifically to people with developmental disabilities.

Policy Devolution and Program Accountability

The 1990s are recognized as the decade of "devolution" of federal policy towards more state and local control over programs, resources, and decisions. Control over policy and program decisions has perceptively shifted from the federal government to states and to local government entities. This devolutionary movement of policy has been coupled with an expectation for "accountability" for results from states and locales. State and local governments, community programs and others who receive federal funding are required to provide evidence of the outcomes produced through the use of federal dollars, according to the 1994 Government Performance and Results Act (GPRA). The logic of GPRA is that programs that receive federal dollars and produce valued outcomes for our nation and its citizens should continue; programs that produce little or no valued outcomes should be redesigned or discontinued. Resources are too precious and our nation's taxpayers should expect no less a formula for success.

Given the range of programs and funding streams that run between federal agencies, state entities and local organizations for the benefit of 50 million Americans with disabilities this is no small task. Statutory definitions of disability exist in 50 federal acts and programs. As a result of these 50 federal acts and programs, billions of dollars flow from federal agencies to state and local governments and organizations on behalf of people with disabilities. What do we know about the results of these federally funded programs?

The federal government produces or supports many databases that include information about disability. The key population-based surveys for working age people with disabilities are the Current Population Survey, the National Health Interview Survey and the Survey of Income and Program Participation. There are about 39 national databases including household and/or person based surveys, provider based data and administrative data. Despite the number of databases, problems obtaining adequate outcome data persist, particularly as it relates to the mandates of GPRA, including:

- o Little that is known about subgroups of people with disabilities such as people with developmental disabilities;
- o Typical measures of disability, such as Activities of Daily Living that are not effective in measuring people with cognitive impairments or not particularly relevant for children;
- o Disability data that continue to be embedded in a health/medical research framework, rather than an independent living framework that recognizes the unique nature of disability as embodied in current legislation, as opposed to a standardized and program specific definition of disability;

- o No ongoing measures of quality of life of people with disabilities over time which leaves large gaps in our knowledge; and
- o Multiple policy/program definitions of disabilities which pose challenges for integrating and/or comparing data sets, and making inferences that reflect how federally funded programs produce outcomes that represent the whole of a person's life.

Disability Research and Independent Living

The need to generate data to assess whether programs and services are being effective is not new in the disability field. Most programs providing services to those with disability sponsored evaluation studies under mandates from Congress in the 1970s and 1980s. The types of data or indicators used in these evaluation studies included:

- o Compliance with intentions or requirements, such as checking whether programs were complying with federally required or recommended procedures;
- o Diagnostic measures of severity, such as using the Diagnostic and Statistical Manual to assess the severity of a person's "case" and to use such a scale to track changes in a person's "improvement";
- o Composite scales of functioning, such as Activities of Daily Living used to judge an individual's capacity to care for himself or herself, or independent living capacity; and
- o Clinical judgements of progress, where decisions were often made by one or two health professionals regarding a person's rehabilitation in some specific life area.

In recent years the demand for disability data and information about outcomes has grown louder and more persistent. Beginning with the enactment of the Americans with Disabilities Act (ADA) in 1990 and the articulation of goals for the people with disabilities (equality of opportunity, full participation, independent living, and economic self-sufficiency), policy makers, the research community and the disability community have increasingly sought the development of outcome indicators and measures that will enable monitoring of the nation's progress in meeting these goals. Complementary legislation for people with developmental disabilities - - i.e., the Developmental Disabilities Assistance and Bill of Rights Act – the goals of self-determination, integration, choice, productivity, and empowerment for 5 million Americans has also produced an increasing need for outcomes data.

As a result of social legislation such as the ADA, one of the most profound influences on both the process and content of disability data collection and research in recent years has been the increased involvement of people with disabilities. People with disabilities, in general, have become increasingly involved in all aspects of data collection and research including:

- o Setting the data collection and research agenda;
- o Developing data and research questions;
- o Participating in carrying out the data collection and research as interviewees or survey participants, and as action researchers or consultants or advisors; and
- o Meaningfully analyzing data collection and research findings.

This increased participation has meant that the research agenda is broader than it has ever been as

people with disabilities increasingly bring parameters of independent living to the data collection and research agenda.

Notwithstanding this progress, few, if any, databases and/or outcome models exist that can meet the challenge of the: (a) "policy devolution" and "program accountability" paradigm, and (b) "disability research" and "independent living" paradigm as it relates to people with developmental disabilities. Such a database and outcome model should be: susceptible to local control; valid and reliable; person-centered; and, oriented towards issues involving individual quality of life (e.g., choice, integration) As the nation moves towards a new millennium, it is vital that we establish a dialogue and build a consensus on how to assess whether or not publicly funded programs, services, and supports produce valued outcomes for people.

One existing database and outcome model can meet this challenge. It is known as the Personal Outcomes database and outcomes measurement model, and it belongs to The Council on Quality and Leadership In Supports for People with Disabilities (The Council). The following sections describe the genesis, definition, and use of the Personal Outcomes database and model.

PERSONAL OUTCOMES

During the mid-1980s The Council published standards and conducted a national accreditation program for organizations that provided services to people with developmental disabilities. The Council performed a national leadership role in the design and dissemination of habilitation standards that emphasized the interdisciplinary process, individualized program planning, behavior intervention and the promotion of legal rights. In the early 1990s The Council began to reexamine the role of accreditation. With the publication of the *Outcome Based Performance Measures* in 1993, The Council offered a challenge to the traditional assessment of quality in human services. The *Outcome Based Performance Measures* were developed from focus group meetings and individual interviews with people with disabilities. They describe the outcomes or results that people with disabilities want from their services or supports. In other words, the quality of the service or support is determined by the recipient of the service or support, not the provider.

In succeeding years the *Outcome Based Performance Measures* underwent critical review by professionals in the field of disabilities as well as statistical analyses for purposes of validity and reliability. Using the established measures as The Council's new accreditation tool, data were carefully collected and began to be maintained in a data repository warehouse. With the support from the Health Care Financing Administration, in 1995 The Council developed a data base of 447 individuals who participated in interviews during accreditation reviews with the *Outcome Based Performance Measures* at 54 organizations in 16 states throughout the United States. The outcomes and the identified individualized organizational supports that facilitated the outcomes were entered into a data base. In 1997, The Council published the methodology used in the gathering and verification of the data, the factor analysis, and the resulting reformulation of the personal outcomes. Based upon the factor analysis, in 1997, The Council issued a revised edition of the *Personal Outcome Measures* that contained 25 outcome measures in seven domains. The 25 outcome measures are:

Personal Outcome Measures

IDENTITY

- People choose personal goals.
- People choose where and with whom they live.
- People choose where they work.
- People have intimate relationships.
- People are satisfied with services.
- People are satisfied with their personal life situations.

AUTONOMY

- People choose their daily routine.
- People have time, space, and opportunity for privacy.
- People decide when to share personal information.

	People use their environments.
AFFILIATION	<p>People live in integrated environments.</p> <p>People participate in the life of the community.</p> <p>People interact with other members of the community.</p> <p>People perform different social roles.</p> <p>People have friends.</p> <p>People are respected.</p>
ATTAINMENT	<p>People choose services.</p> <p>People realize personal goals.</p>
SAFEGUARDS	<p>People are connected to natural support networks.</p> <p>People are safe.</p>
RIGHTS	<p>People exercise rights.</p> <p>People are treated fairly.</p>
HEALTH	<p>People have the best possible health.</p>
WELLNESS	<p>People are free from abuse and neglect.</p> <p>People experience continuity and security.</p>

Personal Outcome Domains

The seven outcome domains and their definitions are:

Identity - Outcomes in this category give us a sense of how people express themselves as unique individuals. This is revealed through the things they want, the major life choices they make, the people they are close to, and their sense of satisfaction. We express our identity through the choices we make. Our decisions about personal goals, where we work and live, intimate relationships, and our definitions of satisfaction show the different ways we express our individual identity. As individual people, we define who we are and who we want to become at various points in our lives. Our previous life experiences, our current expectations, opportunities and preferences, and our dreams and hopes for the future are essential parts of our identity. People who want to know and support us need to learn about and understand all of these dimensions.

Autonomy - Autonomy is the way we define and control our surroundings and the events that are closest to us-- our physical environment, daily schedule, our needs for privacy, and control over

privileged and personal information. Autonomy is about personal control over life events. Autonomy begins with our ability to define personally important issues and express preferences. It also requires that others show respect for our choices. We make decisions about whom we invite into our personal space. As a very practical matter, autonomy enables us to tell others to go away and leave us alone for a period of time, if that is what we want. We also decide when and how personal information is shared. We decide what information is shared and with whom. Autonomy allows us to fully use and access the places where we live, work, and engage in other activities. We exercise independence and control over the space around us, with modifications and adaptations if needed. Autonomy also means that we make decisions about everyday routines and activities. When we wake up or go to bed, what we wear, when we have our meals, how we organize our day--all of these decisions are how we express our personal styles, preferences, and differences.

Affiliation - Affiliation describes our connections to other people. Each of us chooses who we want to spend time with, where and when we get together, and what we do. These relationships add dimension to our lives. They expand our experiences and enrich how other people view and interact with us. The community is the place where we meet and interact with friends, families, neighbors, co-workers, peers, and other people. These opportunities and experiences give us a sense of belonging and connection. When we join in the life of the community, we meet friends and peers and participate in the variety of activities and experiences that the community offers. We learn new roles, develop new relationships, build alliances, and discover new possibilities.

Attainment - Attainment looks at how people define success in both personal and social terms. In some instances, people define goals and services in very personal terms. At other times, services and goals can reflect commitment to a group of people, an association, a cause, and even a sense of community. People find some degree of individual motivation by successful accomplishment. This motivation is individually defined and varies from person to person. Time frames, types, and levels of support, and the person's definition of success influence the choice of individual goals and services and supports.

Safeguards - Safeguards help us feel secure and safe. Sometimes, we feel safer because of the people around us. These close family members and friends are as concerned with our well being as we ourselves are. With their support, we feel greater protection and strength. We know that we can count on them to act on our behalf. In the service and support organization, health and safety codes, building ordinances, and other licensing requirements are clearly defined. Complying with these requirements will promote, but not guarantee, safety. It is important to adhere to these guidelines for environmental safety.

Rights - People with disabilities have the same rights as all other citizens. People identify which rights are most important to them and organizations assist each person to fully exercise his or her rights. Supporting people to exercise their rights goes well beyond removing barriers. We begin with information, education, and discovery of how each individual identifies rights for him or herself.

Health and Wellness - Health and wellness includes the outcomes of best possible health, freedom from abuse and neglect, and continuity and security. Each of these outcomes will have a different definition and priority for each person. Services and supports address physical and mental health needs to enable each person to experience the best possible health given his or her unique profile and status. Another aspect of personal well being is the impact of change. Services and supports should promote continuity and security for people.

The Importance of Personal Outcomes

Personal outcomes are important because they put listening to the person and learning from the person at the center of organizational life. The *Personal Outcome Measures* enable organizations to identify peoples' priorities. Knowing peoples' priority outcomes influences both individual and organizational behavior. Employees pay attention to the small, but personal, aspects of service and support that are often the keys to outcome attainment.

Personal outcomes also focus attention on the whole person. The personal outcome approach does not allow employees to apply different standards to different areas of the person's life. For example, certain requirements associated with vocational rehabilitation may apply while the person receives psychiatric services. Medicaid waiver regulations define quality in the living environment. Each of these sets of regulation applies only to a part of the person's life. The individual's existence is literally divided among the various agencies and programs that provide support and service. In contrast, personal outcomes apply to the whole person – across services and settings.

When organizations realize that services and supports are methods, and not ends in themselves, they become more thoughtful in connecting services with priority outcomes. Staff organize around outcomes. They emphasize the supports and contribute to outcomes. Employees begin to question the purchase and continuation of services that may have a strong constituency, but lead to no personal outcomes. Outcomes then promote accountability. The question becomes, "If you cannot demonstrate a connection between peoples' outcomes and program process, why are you still paying for and operating the program?"

Data Collection and Personal Outcomes

A set of data collection instruments are used during a personal interview format for an individual with disabilities and scored by trained interviewers. Items are scored in a dichotomous format using standardized administration procedures as 'Yes' the specific outcome is present for the individual or 'No' the specific outcome is not present. The interview usually takes between 1.5 and 2 hours per individual. The individual may be the source of the information for the interview or staff or family may respond. Items are scored individually by the interviewers using pencil-paper forms and the data are sent to The Council's main office to be entered into a database and checked.

Ongoing personal outcome measurement enables an organization to evaluate its performance using the data in a number of ways (a) over time with its own baseline, (b) with other local or state-wide organizations of comparable size and scope, and (c) with the national data.

The next section presents findings from data mining activities conducted by The National Center on Outcomes Research (NCOR) on 4 years of personal outcomes data collected by The Council.

FINDINGS

The Council's Data Warehouse

As of 1998, the outcome data warehouse has stored and consolidated data from 1,851 interviews of individuals with disabilities which includes data about (a) characteristics of the organization where the individual resides, (b) demographic characteristics of the individual, and (c) the individual's responses to the outcome interview. An additional 600 records are currently being added to the data warehouse; once entered, consolidated data from 2,451 interviews will be available for mining. This data warehouse has become the core of The Council's tools. Data have been collected, entered, and cleaned then put into a format accessible to the organization. There are 158 variables in a consolidated data warehouse. The Council uses the Statistical Package for the Social Sciences (SPSS) Base 9.0 software to conduct analyses of variables in the data warehouse.

Initially, The Council also used an SPSS format to maintain its data from 1,851 interviews formatted into 158 variables. More recently, The Council has begun to use Microsoft Access and relational data tables as the foundation for its data warehouse and is presently in the process of: (a) field-testing its data collection software, (b) migrating its SPSS data to Microsoft Access, and (c) moving its data warehouse to the World Wide Web. Once the data warehouse is web connected, a range of audiences will be able to conduct select queries and produce results that are of use to them in their work.

The Council has a mission statement of improving the lives for persons with developmental disabilities and intends to use these data for that mission. One way to do so is by investigating organizational and personal characteristics which contribute to better outcomes through multidimensional modeling and through national and international dissemination of the data.

Data mining techniques. Data mining uses the traditional statistical techniques of modeling which include regression, logistic regression, association analysis, clustering, neural networks, decision trees, and discriminant function. The term data mining is reserved for a large, relational, and consolidated data set (the data warehouse) which is statistically analyzed to: address stated research problems; provide prescribed data 'runs' on request from customers, researchers, policy makers, and advocates; and, to conduct online analytic processing explorations. Traditionally used as an economic analytic tool for businesses and organizations, data mining was developed to meet the ever urgent information technology (IT) needs of product and service marketers. Data mining is ultimately about smart decision making based on data collected, in this instance, from consumers with disabilities.

Data Analyzed. Variables selected for analysis are: (a) the individual characteristic referred to as the primary disability of the person; and (b) the organizational characteristics known as the individual's primary funding source, the living arrangement for the individual, and the size of the organization serving the individual. In addition, data about the reviews and interviews at organizations are analyzed.

Specific Findings

Finding #1. Descriptive Data for Reviews and Interviews. From August, 1993 through December, 1997 there were 268 accreditation reviews conducted with the *Outcome Measures* at 199 different organizations. The organizations represent a broad spectrum of service and support providers including state-wide family support and respite services and a variety of vocational, day, and residential options. Organization size ranged from less than 10 to over 1,000 individuals receiving services and/or supports. Reviews were conducted in 27 states across the United States. The table below provides more detailed data.

STATE	# Orgs.	# of Reviews	# of Interviews	# of Interviews as %
AR	5	6	56	3.0%
CO	2	3	21	1.1%
CT	1	1	5	0.3%
GA	2	2	11	0.6%
IA	7	12	99	5.3%
IL	34	36	251	13.5%
IN	2	3	34	1.8%
KS	1	1	5	0.3%
KY	3	4	30	1.6%
LA	5	5	35	1.9%
MD	4	4	32	1.7%
MI	1	1	27	1.5%
MN	1	1	15	0.8%
MO	2	4	48	2.6%
MT	19	28	119	6.4%
NC	42	65	274	14.7%
ND	29	41	303	16.3%
NE	1	3	18	1.0%
NJ	3	4	48	2.6%
NM	4	6	48	2.6%
NV	3	4	51	2.7%
OK	2	3	37	2.0%
PA	2	3	57	3.1%
SD	16	17	144	7.7%
TX	5	6	65	3.5%
UT	2	3	17	0.9%
WI	1	2	11	0.6%
Total # of States = 27	Total # of Orgs. = 199	Total # of Reviews = 268	Total # of Interviews = 1,851	

Finding #2. Descriptive Data for People Interviewed. Descriptive statistics are presented for the demographic variables of: Gender, Age Group, Information Source, Primary Funding, and Living Arrangement as they relate to the 1,851 individuals who were interviewed.

VARIABLE	TOTAL
	N (%)
Gender	
Male	946 (56.18)
Female	738 (43.82)
Age Group	
< 6	52 (3.13)
6 – 18	142 (8.52)
19 – 65	1,381 (83.14)
> 65	86 (5.18)
Information Source	
Self	868 (46.7)
Staff Member	620 (33.3)
Family Member	316 (17.0)
Other	47 (3.0)
Primary Funding	
ICF/MR	427 (23.1)
HCBW	474 (25.6)
State	288 (15.6)
Private	21 (1.7)
Living Arrangement	
Natural Family	201 (14.0)
Foster Family	46 (3.2)
Supervised Living (24 hr. support)	903 (62.8)
Supported Living (< 24 hr. support)	215 (15.0)
Independent Living	73 (5.1)

Finding #3. Crosstabulations Data. Descriptive statistics are presented below for the mean percent of outcomes reported across the 7 domains by primary funding source, by different living arrangements, by size of organization, and by primary disability. A visual inspection of the means allows for determination of trends, patterns, and possible relationships.

Finding #3a. Crosstabulations for Outcomes By Primary Funding Source. In terms of trends or patterns, a review of the domain means across the four primary funding sources indicates that for Identity, Autonomy, Affiliation, Attainment, and Rights, outcomes for individuals are clearly better the more local the funding source appears to be. While the actual number of instances of individuals represented in the category 'Private Pay' are 21, and may not be considered statistically significant, the data suggests that the closer the control of resources is to the individual with a disability the better their outcomes. In general, Safeguards parallels Health in being uniform across variables. There is no significant statistical difference.

**MEAN PERCENT OF OUTCOMES ACHIEVED BY
PRIMARY FUNDING SOURCE UP TO 1998**

		PRIMARY FUNDING			
		ICF/MR	HCBW	STATE	PVT PAY
DOMAINS	Identity	47	61	68	78
	Autonomy	60	88	88	94
	Affiliation	38	62	65	76
	Attainment	51	69	72	87
	Rights	15	26	43	61
	Health	82	83	82	91
	Safeguards	77	80	83	71

Finding #3b. Crosstabulations for Outcomes By Different Living Arrangements. In terms of trends or patterns, a review of the domain means across the five types of living arrangements indicates that for Identity, Autonomy, Affiliation, Attainment, and Rights, outcomes are clearly better the closer the individual is to the local community and the closer the individual is to controlling his/her living arrangement. In general, Safeguards parallels Health in being uniform across variables. There is no significant statistical difference.

**MEAN PERCENT OF OUTCOMES ACHIEVED IN DIFFERENT LIVING
ARRANGEMENTS UP TO 1998**

		LIVING ARRANGEMENTS				
		natural family	foster family	supervised living	supported living	independent living
DOMAINS	Identity	72	72	51	68	80
	Autonomy	87	64	77	94	98
	Affiliation	68	70	47	73	84
	Attainment	74	74	57	74	83
	Rights	58	53	19	41	63
	Health	83	76	89	85	85
	Safeguards	89	75	78	82	70

Finding #3c. Crosstabulations for Outcomes By Size of Organization. There are a few clear patterns or trends presented by the mean outcomes in domains across the six different types of organization size presented in the table below. First, individuals associated with organizations serving/supporting 25 or fewer people have achieved more outcomes in every domain than have individuals associated with organizations serving/supporting 500 or more people. Second, the highest level of outcomes achieved across domains and size of organization appear in the Autonomy domain; the lowest level of outcomes achieved across domains and size of organization appear in the Rights domain.

**PERCENT OF OUTCOMES ACHIEVED IN DIFFERENT SIZE ORGANIZATIONS UP
TO 1998**

		SIZE OF ORGANIZATION					
		< 25 People	26-50 People	51-100 People	101-200 People	201-500 People	> 500 People
DOMAINS	Identity	56	62	61	64	36	50
	Autonomy	85	83	85	85	85	63
	Affiliation	58	60	60	60	54	44
	Attainment	69	72	73	70	60	54
	Rights	36	26	32	42	39	22
	Health	78	80	80	80	85	78
	Safeguards	78	82	80	82	85	74

Finding #3d. Crosstabulations for Outcomes By Primary Disability. There are a few clear patterns or trends presented by the mean outcomes in domains across the 12 different types of primary disability categories presented in the table below, save one. The highest levels of outcomes achieved across domains and primary disability category appear in the Autonomy, Health, and Safeguards domains; the lowest level of outcomes achieved across domains and primary disability category appear in the Rights domain.

PERCENT OF OUTCOMES ACHIEVED BY PEOPLE WITH DIFFERENT PRIMARY DISABILITIES UP TO 1998

PRIMARY DISABILITY													
		Other	Profound MR	Severe MR	Moderate MR	Mild MR	CP	Autism	Seizure	Hearing	Vision	TBI	MI
DOMAINS	Identity	61	49	53	57	65	66	74	46	65	56	72	58
	Autonomy	82	69	81	85	88	82	87	85	97	84	75	88
	Affiliation	60	36	48	57	67	63	67	68	65	50	67	60
	Attainment	67	56	55	64	72	74	78	64	67	50	83	61
	Rights	43	38	26	26	38	59	32	50	38	13	50	27
	Health	56	80	82	81	83	83	89	86	96	83	83	78
	Safeguards	80	77	80	80	82	88	83	81	81	81	75	79

Additional Data Displays

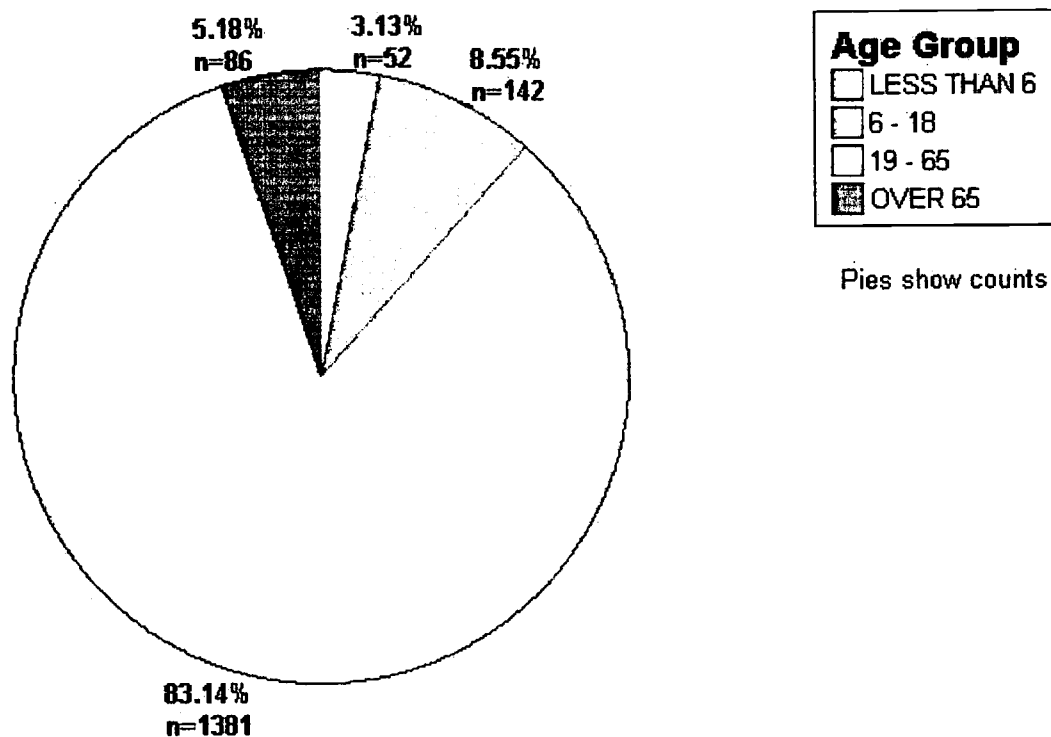
Graphical displays related to Finding #2 and Finding #3a-#3d, including specific crosstabulation findings for outcomes can be viewed by going to the following locations in this report:

1. Chart 1 - Age Group and Gender, Number and Frequency
2. Chart 2 - Primary Disability, Number and Frequency
3. Chart 3 - People By Living Arrangement, Number and Frequency
4. Chart 4 - Information Source By Disability, Number
5. Chart 5 - People Interviewed By Communication Method, Number and Frequency
6. Chart 6 - Day Services/Supports Provided, Number and Frequency
7. Chart 7 - Outcomes By Primary Funding Source, Percent
8. Chart 8 - National Outcomes Achieved & Supports Provided, Percent
9. Chart 9 - Outcomes By Living Arrangements, Percent
10. Chart 10 - Outcomes By Primary Disability, Percent
11. Chart 11 - Outcomes By Age Group, Percent
12. Chart 12 - Outcomes By Size of Organization, Percent

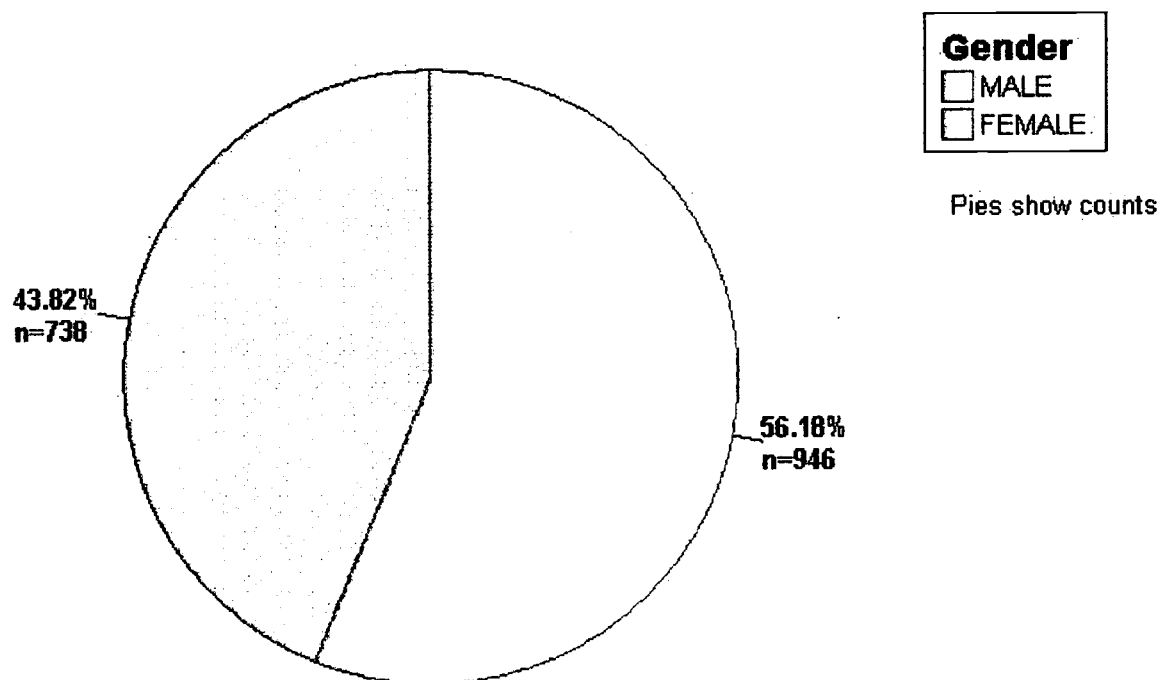
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NATIONAL OUTCOME STATISTICS UP TO 1998

Number and Percent of People by Age Group



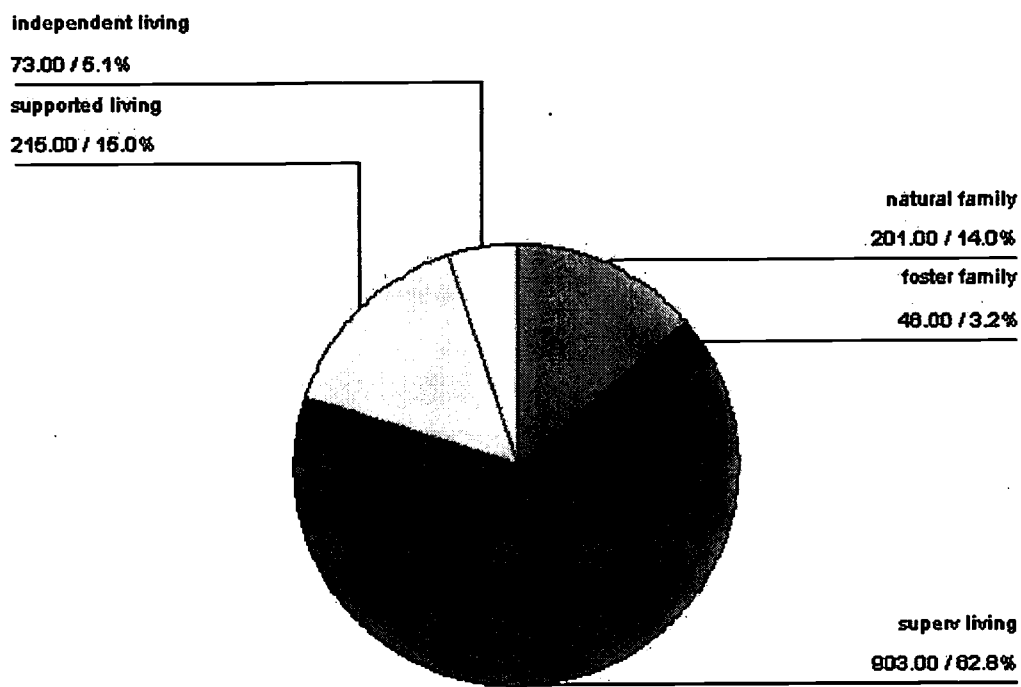
Number and Percent of People by Gender



**NUMBER AND PERCENT OF PEOPLE BY PRIMARY DISABILITY UP TO
1998**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Other	288	15.6	15.6	15.6
	Profound MR	249	13.5	13.5	29.0
	Severe MR	229	12.4	12.4	41.4
	Moderate MR	298	16.1	16.1	57.5
	Mild MR	392	21.2	21.2	78.7
	CP	67	3.6	3.6	82.3
	Autism	60	3.2	3.2	85.5
	Seizure	29	1.6	1.6	87.1
	Hearing	9	.5	.5	87.6
	Vision	8	.4	.4	88.0
	TBI	6	.3	.3	88.3
	MI	216	11.7	11.7	100.0
	Total	1851	100.0	100.0	

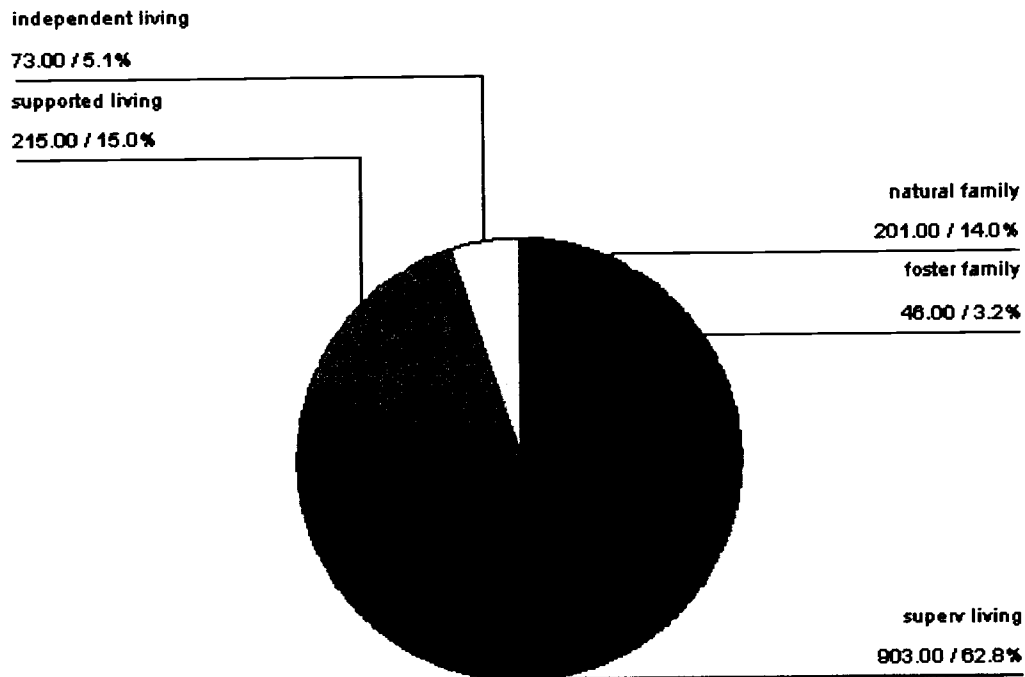
Frequency/Percent Of People Served In Different Living Arrangements Up To 1998



Frequency & Percent of People Served in Different Living Arrangements Up To 1998

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	natural family	201	10.9	14.0	14.0
	foster family	46	2.5	3.2	17.2
	superv living	903	48.8	62.8	80.0
	supported living	215	11.6	15.0	94.9
	independent living	73	3.9	5.1	100.0
	Total	1438	77.7	100.0	
Missing	System	413	22.3		
Total		1851	100.0		

Frequency/Percent Of People Served In Different Living Arrangements Up To 1998



Frequency & Percent of People Served in Different Living Arrangements Up To 1998

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	natural family	201	10.9	14.0	14.0
	foster family	46	2.5	3.2	17.2
	superv living	903	48.8	62.8	80.0
	supported living	215	11.6	15.0	94.9
	independent living	73	3.9	5.1	100.0
	Total	1438	77.7	100.0	
Missing System		413	22.3		
Total		1851	100.0		

NUMBER OF PEOPLE BY DISABILITY AND BY LIVING ARRANGEMENT UP TO 1998
Count

		LIVING ARRANGEMENT					Total
		natural family	foster family	superv living	supported living	independent living	
PRIMARY DISABILITY	Other	34	7	29	10	2	82
	Profound MR	14	4	203	4	1	226
	Severe MR	16	4	165	12		197
	Moderate MR	26	11	171	45	7	260
	Mild MR	44	8	147	99	43	341
	CP	24	3	20	7	2	56
	Autism	11	1	28	5		45
	Seizure	10	2	11			23
	Hearing	1	1	4	2	1	9
	Vision	1		5	1		7
	TBI	2		1			3
	MH	18	5	119	30	17	189
Total		201	46	903	215	73	1438

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**NUMBER AND PERCENT OF PEOPLE BY PRIMARY DISABILITY UP TO
1998**

	Frequency	Percent	Valid Percent	Cumulative Percent
Other	288	15.6	15.6	15.6
Profound MR	249	13.5	13.5	29.0
Severe MR	229	12.4	12.4	41.4
Moderate MR	298	16.1	16.1	57.5
Mild MR	392	21.2	21.2	78.7
CP	67	3.6	3.6	82.3
Valid Autism	60	3.2	3.2	85.5
Seizure	29	1.6	1.6	87.1
Hearing	9	.5	.5	87.6
Vision	8	.4	.4	88.0
TBI	6	.3	.3	88.3
MI	216	11.7	11.7	100.0
Total	1851	100.0	100.0	

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**FREQUENCY AND PERCENT OF PEOPLE INTERVIEWED BY METHOD OF
COMMUNICATION UP TO 1998**

	Frequency	Percent	Valid Percent	Cumulative Percent
FULLY VERBAL	794	42.9	42.9	42.9
PARTIALLY VERBAL	621	33.5	33.5	76.4
SIGN/GESTURE	118	6.4	6.4	82.8
Valid DEVICE	45	2.4	2.4	85.3
STAFF HELP	192	10.4	10.4	95.6
OTHER	81	4.4	4.4	100.0
Total	1851	100.0	100.0	

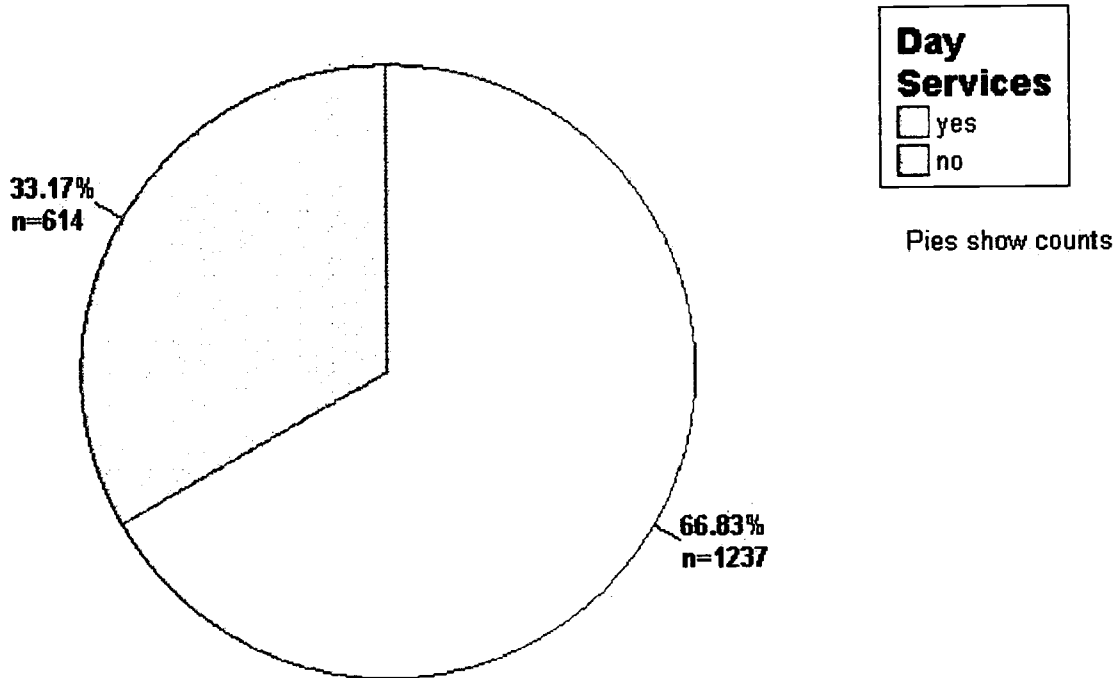
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**FREQUENCY AND PERCENT OF PEOPLE INTERVIEWED BY METHOD OF COMMUNICATION AND BY INFORMATION SOURCE
UP TO 1998**

	<i>INFORMATION SOURCE</i>				<i>Total</i>
	<i>Self</i>	<i>Staff Member</i>	<i>Family Member</i>	<i>Other</i>	
FULLY VERBAL					
<i>Count</i>	544	180	61	9	794
<i>% within Info Source</i>	62.7%	29.0%	19.3%	19.1%	42.9%
PARTIALLY VERBAL					
<i>Count</i>	251	224	128	18	621
<i>% within Info Source</i>	28.9%	36.1%	40.5%	38.3%	33.5%
SIGN/GESTURE					
<i>Count</i>	12	66	35	5	118
<i>% within Info Source</i>	1.4%	10.6%	11.1%	10.6%	6.4%
DEVICE					
<i>Count</i>	11	19	15	.00	45
<i>% within Info Source</i>	1.3%	3.1%	4.7%	.00	2.4%
STAFF HELP					
<i>Count</i>	3	120	65	4	192
<i>% within Info Source</i>	.3%	19.4%	20.6%	8.5%	10.4%
OTHER					
<i>Count</i>	47	11	12	11	81
<i>% within Info Source</i>	5.4%	1.8%	3.8%	23.4%	4.4%
<i>Count</i>	868	620	316	47	1851
<i>% within Info Source</i>	100.0%	100.0%	100.0%	100.0%	100.0%
METHOD OF COMMUNICATION					
<i>Total</i>					

NATIONAL OUTCOME STATISTICS UP TO 1998

Number and Percent of People by Day Services



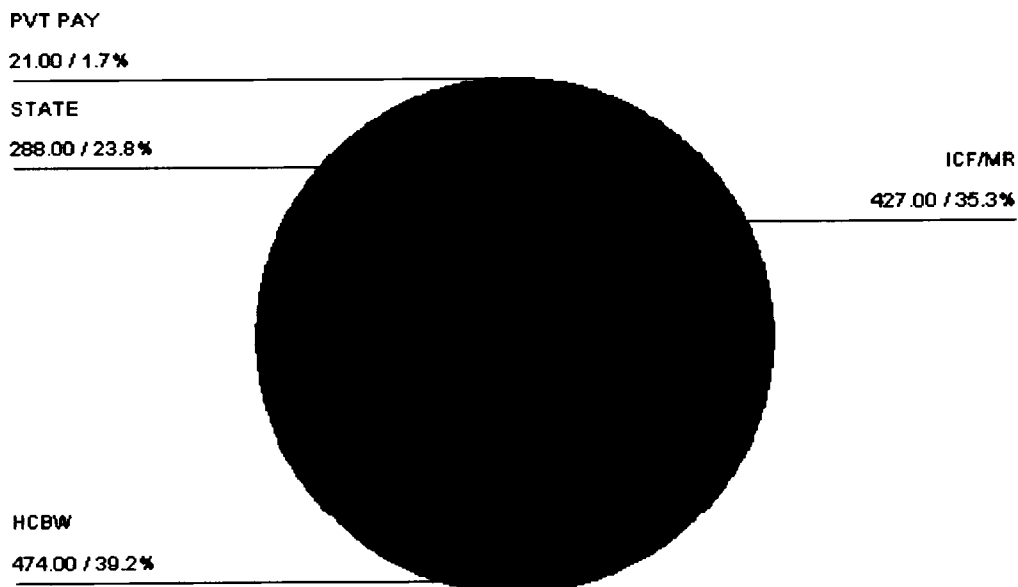
Number and Percent of People by Type of Day Service

Name	Count	Pct of Responses	Pct of Cases
Day Activity Center	302	20.4	32.8
Work Activity Center	242	16.3	26.3
Workshop	231	15.6	25.1
Supported Employment	184	12.4	20.0
Leisure	244	16.5	26.5
Recreational	223	15.1	24.2
Retirement	55	3.7	6.0
Total	1481	100.0	161.0

**FREQUENCY AND PERCENT OF PEOPLE SERVED BY PRIMARY
FUNDING SOURCE UP TO 1998**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	ICF/MR	427	23.1	35.3	35.3
	HCBW	474	25.6	39.2	74.5
	STATE	288	15.6	23.8	98.3
	PVT PAY	21	1.1	1.7	100.0
	Total	1210	65.4	100.0	
Missing	System	641	34.6		
Total		1851	100.0		

**Frequency/ Percent Of People Served By
Primary Funding Source Up To 1998**



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**PERCENT OF IDENTITY OUTCOMES ACHIEVED BY PRIMARY FUNDING SOURCE
UP TO 1998**

		PRIMARY FUNDING				Mean
		ICF/MR	HCBW	STATE	PVT PAY	
IDENTITY	#1-People choose personal goals	25	37	42	58	34
	#2-People choose where and with whom they live	18	52	64	74	43
	#3-People choose where they work	19	37	47	63	34
	#4-People have intimate relationships	60	67	76	68	66
	#5-People are satisfied with services	84	89	87	100	87
	#6-People are satisfied with their personal life situations	79	85	87	89	83
Mean		47	61	68	78	

**PERCENT OF AUTONOMY OUTCOMES ACHIEVED BY PRIMARY FUNDING
SOURCE UP TO 1998**

		PRIMARY FUNDING				Mean
		ICF/MR	HCBW	STATE	PVT PAY	
AUTONOMY	#1-People choose their daily routine	60	90	87	84	79
	#2-People have time, space, and opportunity for privacy	72	90	94	95	85
	#3-People decide when to share personal information	84	88	92	95	88
	#4-People use their environments	57	83	82	89	74
	Mean	68	88	88	94	

**PERCENT OF AFFILIATION OUTCOMES ACHIEVED BY PRIMARY FUNDING
SOURCE UP TO 1998**

	PRIMARY FUNDING				<i>Mean</i>
	<i>ICF/MR</i>	<i>HCBW</i>	<i>STATE</i>	<i>PVT PAY</i>	
<i>#1-People live in integrated environments</i>	3	30	39	78	23
<i>#2-People participate in the life of the community</i>	66	95	92	95	84
<i>#3-People interact with other members of the community</i>	41	73	76	95	63
<i>#4-People perform social roles</i>	13	30	35	47	25
<i>#5-People have friends</i>	47	66	65	79	59
<i>#6-People are respected</i>	60	79	84	68	73
<i>Mean</i>	38	62	65	76	

**PERCENT OF ATTAINMENT OUTCOMES ACHIEVED BY PRIMARY FUNDING
SOURCE UP TO 1998**

		PRIMARY FUNDING				
		ICF/MR	HCBW	STATE	PVT PAY	Mean
ATTAINMENT	#1-People choose services	23	49	55	84	42
	#2-People realize personal goals	79	89	89	90	86
	Mean	51	69	72	87	

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**PERCENT OF RIGHTS OUTCOMES ACHIEVED BY PRIMARY FUNDING
SOURCE UP TO 1998**

		PRIMARY FUNDING				
		ICF/MR	HCBW	STATE	PVT PAY	Mean
RIGHTS	#1-People exercise rights	10	31	32	58	24
	#2-People are treated fairly	21	42	39	63	34
	Mean	15	26	43	61	

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**PERCENT OF HEALTH OUTCOMES ACHIEVED BY PRIMARY FUNDING SOURCE
UP TO 1998**

		PRIMARY FUNDING				<i>Mean</i>
		<i>ICF/MR</i>	<i>HCBW</i>	<i>STATE</i>	<i>PVT PAY</i>	
HEALTH	<i>#1-People have the best possible health</i>	69	75	70	89	72
	<i>#2-People are free from abuse and neglect</i>	86	86	84	84	85
	<i>#3-People experience continuity and security</i>	90	88	90	94	89
	Mean	82	83	82	91	

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**PERCENT OF SAFEGUARDS OUTCOMES ACHIEVED BY PRIMARY FUNDING
SOURCE UP TO 1998**

		PRIMARY FUNDING				Mean
		ICF/MR	HCBW	STATE	PVT PAY	
SAFEGUARDS	#1-People are connected to natural support networks	62	74	46	68	71
	#2-People are safe	92	86	89	78	89
Mean		77	80	83	71	

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National Statistics-Personal Outcome Measures

1998-Graphs

IDENTITY

Outcome #1: People choose personal goals.

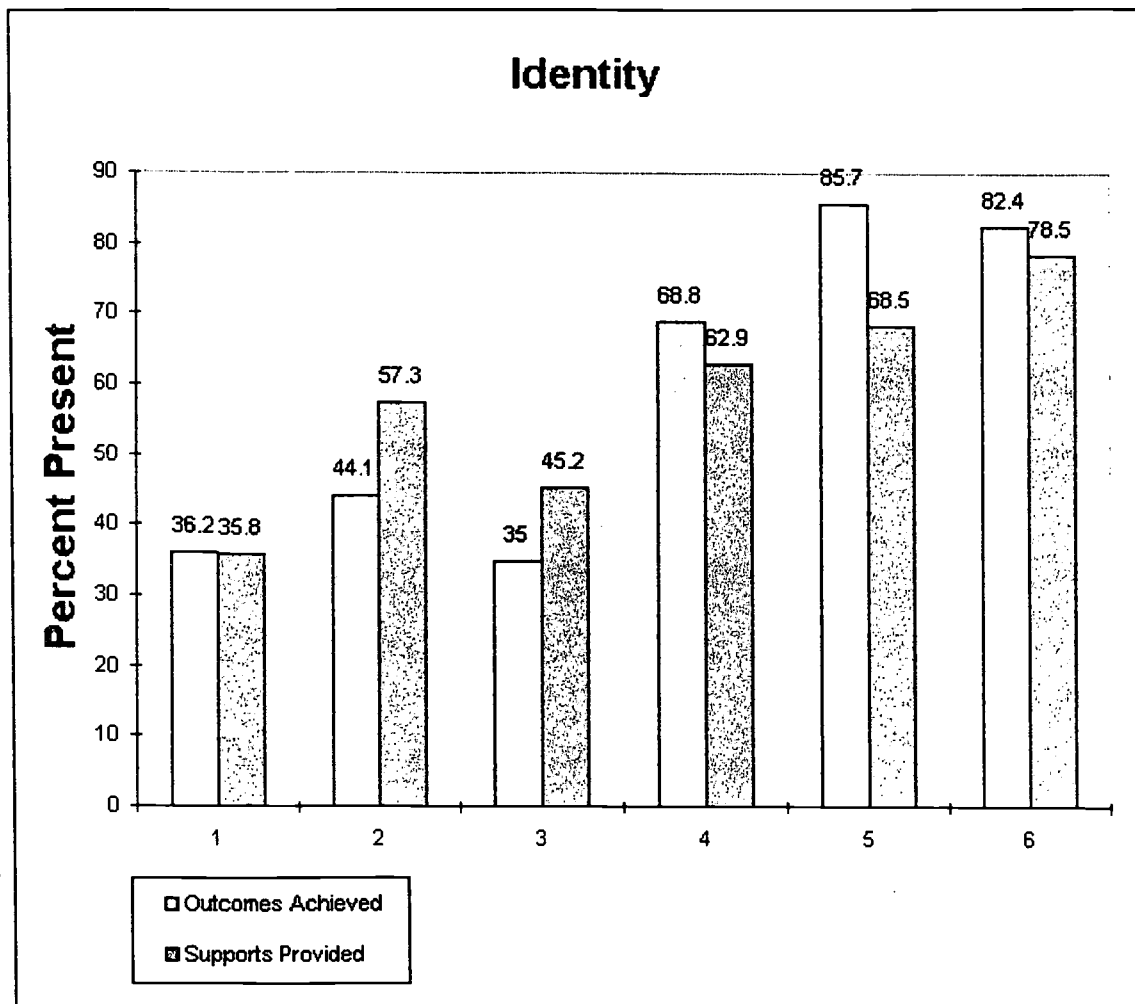
Outcome #2: People choose where and with whom they live.

Outcome #3: People choose where they work.

Outcome #4: People have intimate relationships.

Outcome #5: People are satisfied with services.

Outcome #6: People are satisfied with their personal life situations.



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National Statistics-Personal Outcome Measures

1998-Graphs

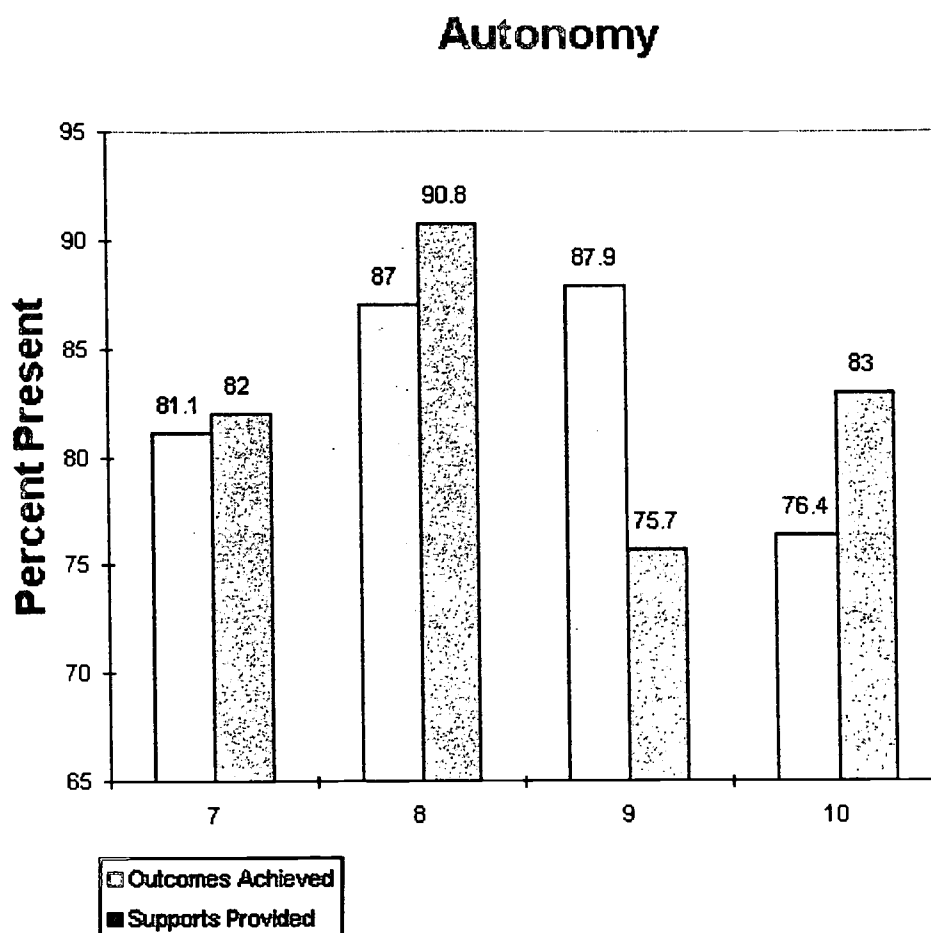
AUTONOMY

Outcome #7:
People choose
their daily
routine.

Outcome #8:
People have
time, space,
and
opportunity for
privacy.

Outcome #9:
People decide
when to share
personal
information.

Outcome #10:
People use
their
environments.



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National Statistics-Personal Outcome Measures

1998-Graphs

AFFILIATION

Outcome #11:
People live in
integrated
environments.

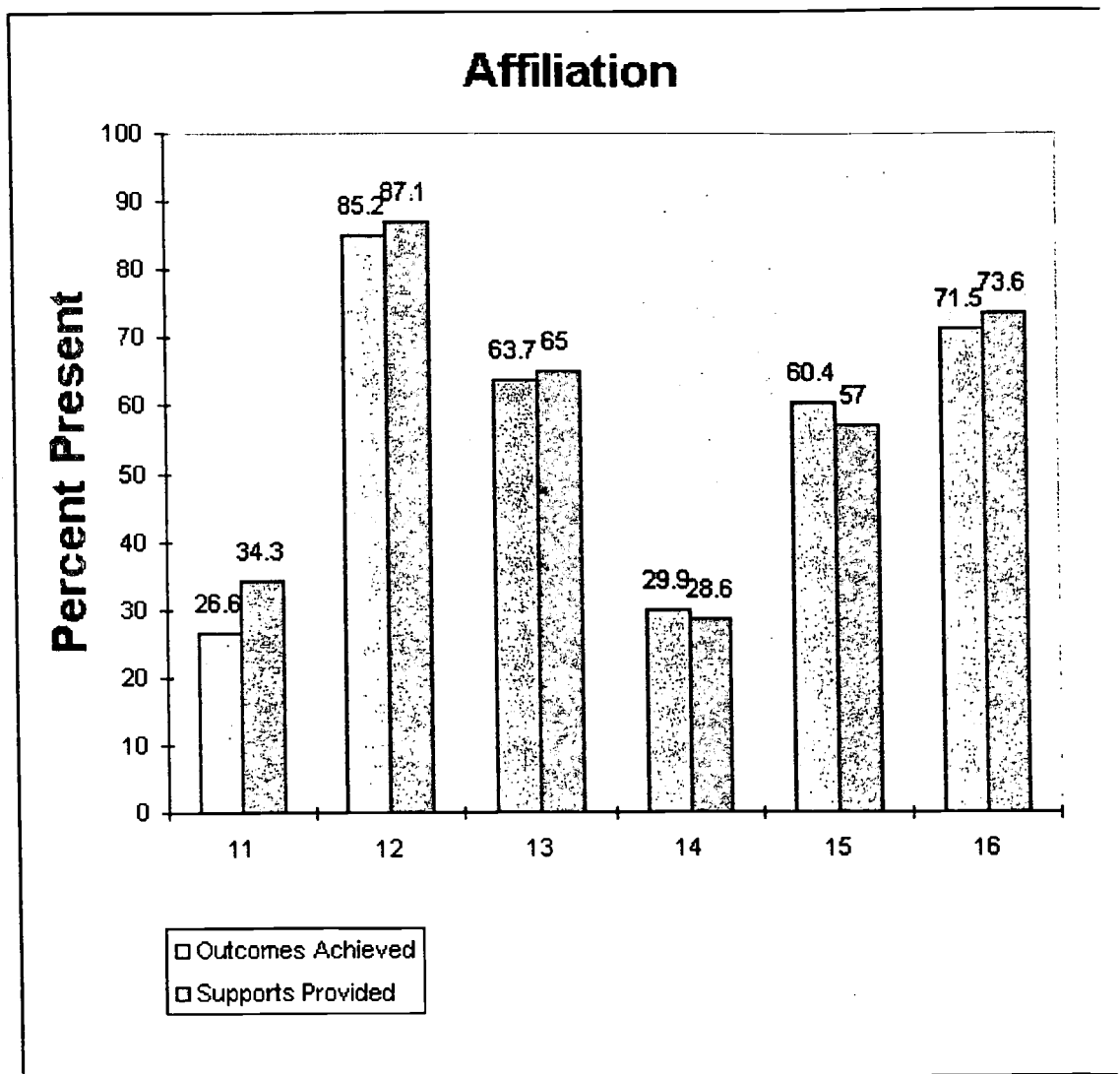
Outcome #12:
People
participate in the
life of the
community.

Outcome #13:
People interact
with other
members of the
community.

Outcome #14:
People perform
social roles.

Outcome #15:
People have
friends.

Outcome #16:
People are
respected.

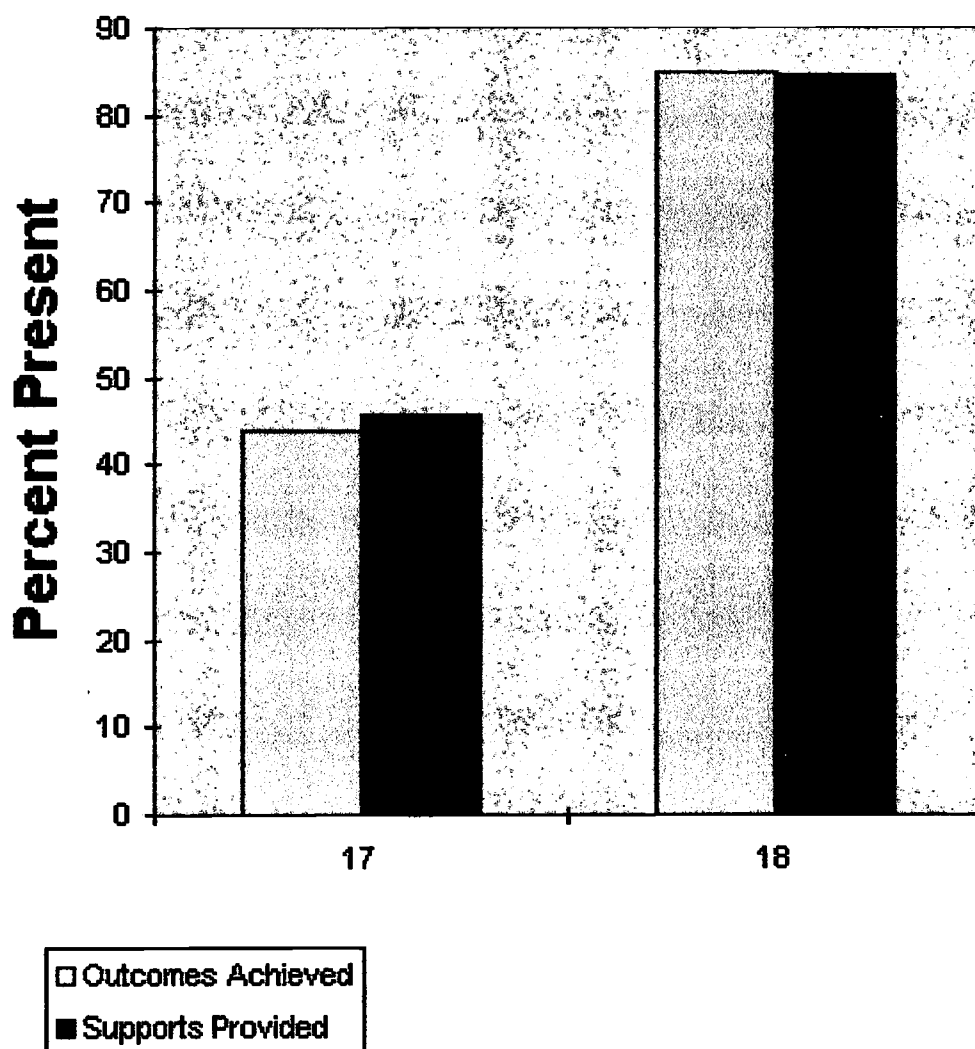


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National Statistics-Personal Outcome Measures

1998-Graphs

Attainment



ATTAINMENT

Outcome #17:
People choose
services

Outcome 318:
People realize
personal goals..

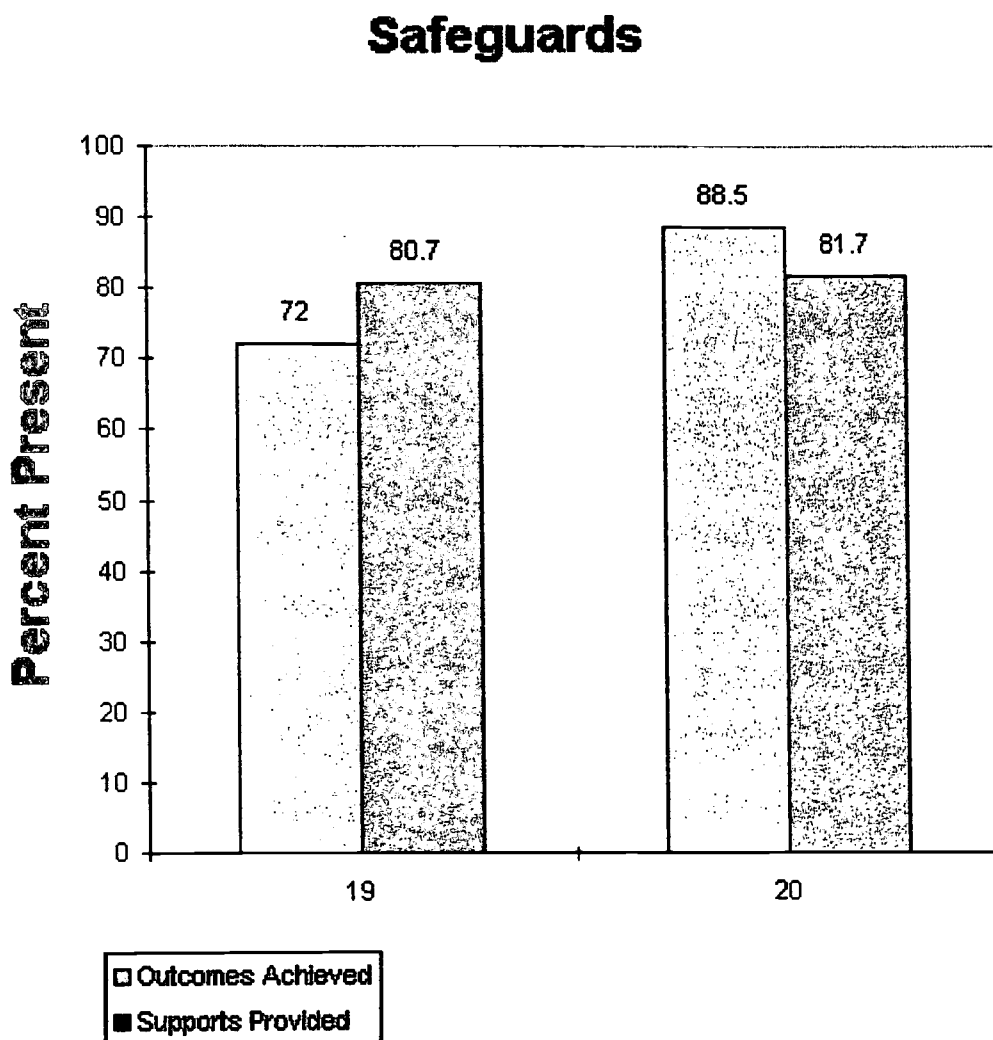
National Statistics-Personal Outcome Measures

1998-Graphs

SAFEGUARDS

Outcome #19:
People are
connected to
natural support
networks.

Outcome #20:
People are safe.



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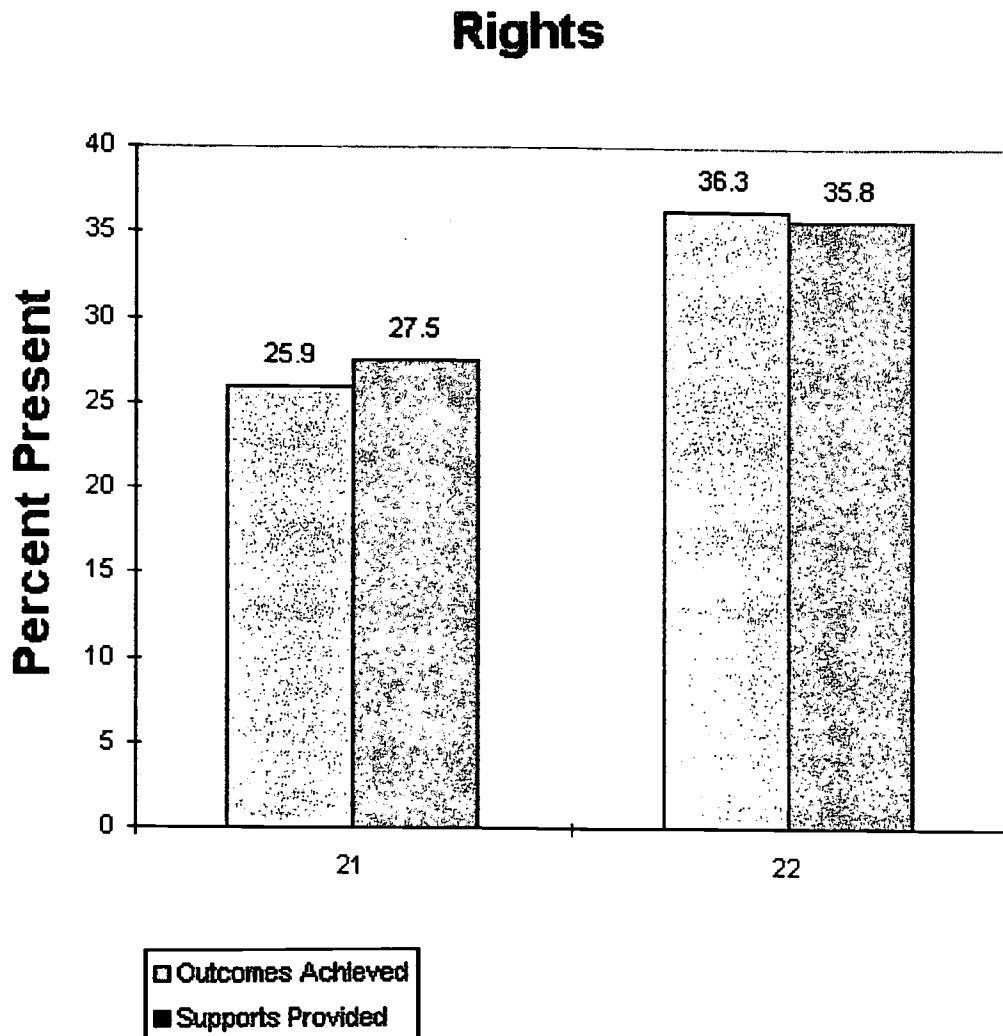
National Statistics—Personal Outcome Measures

1998-Graphs

RIGHTS

Outcome
#21: People
exercise
rights.

Outcome
#22: People
are treated
fairly.



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National Statistics-Personal Outcome Measures

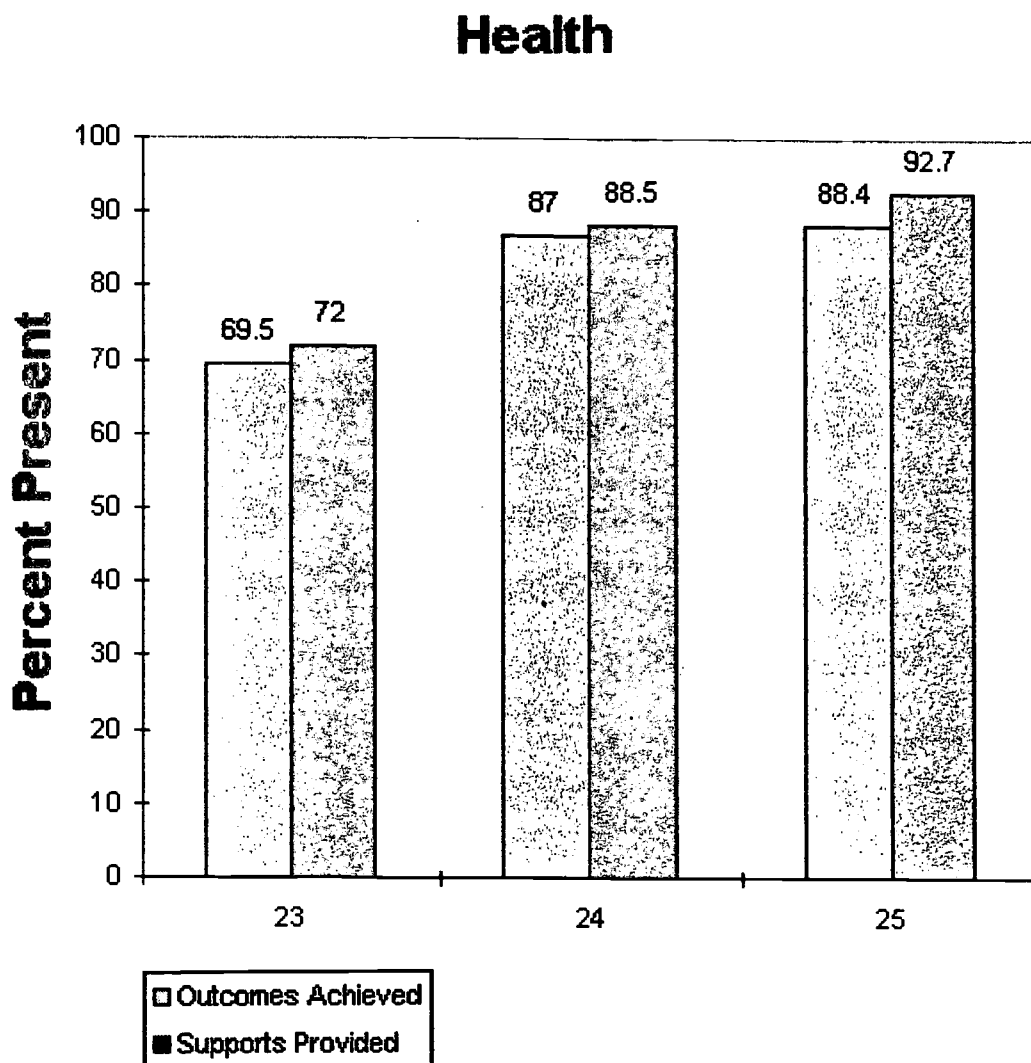
1998-Graphs

HEALTH AND WELLNESS

Outcome
#23: People
have the best
possible
health.

Outcome
#24: People
are free from
abuse and
neglect.

Outcome
325: People
experience
continuity
and security.



**PERCENT OF IDENTITY OUTCOMES ACHIEVED IN DIFFERENT LIVING
ARRANGEMENTS UP TO 1998**

		LIVING ARRANGEMENTS					Mean
		natural family	foster family	supervised living	supported living	independent living	
IDENTITY	#1-People choose personal goals	47	59	30	41	61	36
	#2-People choose where and with whom they live	85	65	33	64	86	45
	#3-People choose where they work	51	52	24	69	57	35
	#4-People have intimate relationships	88	67	61	75	81	68
	#5-People are satisfied with services	87	91	85	87	93	86
	#6-People are satisfied with their personal life situations	84	91	80	87	90	83
	Mean	72	72	51	68	80	

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**PERCENT OF AUTONOMY OUTCOMES ACHIEVED IN DIFFERENT LIVING
ARRANGEMENTS UP TO 1998**

		LIVING ARRANGEMENTS					Mean
		natural family	foster family	superv living	supported living	independent living	
AUTONOMY	#1-People choose their daily routine	91	91	73	95	99	81
	#2-People have time, space, and opportunity for privacy	94	87	81	95	100	86
	#3-People decide when to share personal information	86	89	85	93	94	87
	#4-People use their environments	80	82	68	91	97	75
	Mean	87	64	77	94	98	

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**PERCENT OF AFFILIATION OUTCOMES ACHIEVED IN DIFFERENT LIVING
ARRANGEMENTS UP TO 1998**

	<i>LIVING ARRANGEMENTS</i>					<i>Mean</i>
	<i>natural family</i>	<i>foster family</i>	<i>supervised living</i>	<i>supported living</i>	<i>independent living</i>	
<i>AFFILIATION</i>						
<i>#1-People live in integrated environments</i>	49	49	10	53	78	27
<i>#2-People participate in the life of the community</i>	86	98	79	96	100	84
<i>#3-People interact with other members of the community</i>	83	83	55	84	90	66
<i>#4-People perform social roles</i>	47	46	18	41	60	29
<i>#5-People have friends</i>	64	65	53	77	81	60
<i>#6-People are respected</i>	80	72	66	87	93	73
<i>Mean</i>	68	70	47	73	84	

**PERCENT OF ATTAINMENT OUTCOMES ACHIEVED IN DIFFERENT LIVING
ARRANGEMENTS UP TO 1998**

		<i>LIVING ARRANGEMENTS</i>					<i>Mean</i>
		<i>natural family</i>	<i>foster family</i>	<i>supervised living</i>	<i>supported living</i>	<i>independent living</i>	
<i>ATTAINMENT</i>	<i>#1-People choose services</i>	63	59	32	54	71	43
	<i>#2-People realize personal goals</i>	84	89	81	98	96	85
	<i>Mean</i>	74	74	57	74	83	

**PERCENT OF RIGHTS OUTCOMES ACHIEVED IN DIFFERENT LIVING
ARRANGEMENTS UP TO 1998**

		LIVING ARRANGEMENTS					Mean
		<i>natural family</i>	<i>foster family</i>	<i>superv living</i>	<i>supported living</i>	<i>independent living</i>	
<i>RIGHTS</i>	<i>#1-People exercise rights</i>	51	46	14	35	61	26
	<i>#2-People are treated fairly</i>	65	61	24	47	65	36
<i>Mean</i>		58	53	19	41	63	

**PERCENT OF HEALTH OUTCOMES ACHIEVED IN DIFFERENT LIVING
ARRANGEMENTS UP TO 1998**

		<i>LIVING ARRANGEMENTS</i>					<i>Mean</i>
		<i>natural family</i>	<i>foster family</i>	<i>supervised living</i>	<i>supported living</i>	<i>independent living</i>	
<i>HEALTH</i>	<i>#1-People have the best possible health</i>	69	64	68	76	70	69
	<i>#2-People are free from abuse and neglect</i>	89	76	85	86	91	86
	<i>#3-People experience continuity and security</i>	91	87	89	92	94	90
	<i>Mean</i>	83	76	81	85	85	

**PERCENT OF SAFEGUARDS OUTCOMES ACHIEVED IN DIFFERENT LIVING
ARRANGEMENTS UP TO 1998**

		LIVING ARRANGEMENTS					
		<i>natural family</i>	<i>foster family</i>	<i>supervised living</i>	<i>supported living</i>	<i>independent living</i>	<i>Mean</i>
SAFEGUARDS	<i>#1-People are connected to natural support networks</i>	91	67	64	80	78	71
	<i>#2-People are safe</i>	87	83	91	84	63	88
	<i>Mean</i>	89	75	78	82	70	

PERCENT OF IDENTITY OUTCOMES ACHIEVED BY PEOPLE WITH DIFFERENT PRIMARY DISABILITIES UP TO 1998

PRIMARY DISABILITY

	Other	Profound MR	Severe MR	Moderate MR	Mild MR	CP	Autism	Seizure	Hearing	Vision	TBI	MI	Mean
#1-People choose personal goals	38	26	25	32	46	45	47	28	22	25	83	46	37
#2-People choose where and with whom to live	52	26	31	37	60	66	62	52	56	38	50	47	45
#3-People choose where to work	40	21	19	32	46	53	53	34	33	25	50	40	36
#4-People have intimate relationships	72	55	67	72	76	72	88	72	77	75	100	59	69
#5-People are satisfied with services	87	86	90	87	84	80	89	90	100	88	84	83	86
#6-People are satisfied with their personal life situations	82	84	86	82	83	83	85	83	100	88	67	74	82
Mean	61	49	53	57	65	66	74	46	65	56	72	58	

PERCENT OF AUTONOMY OUTCOMES ACHIEVED BY PEOPLE WITH DIFFERENT PRIMARY DISABILITIES UP TO
1998

PRIMARY DISABILITY

	Other	Profound MR	Severe MR	Moderate MR	Mild MR	CP	Autism	Seizure	Hearing	Vision	TBI	MI	Mean
#1-People choose their daily routines	79	62	78	84	88	88	83	79	100	75	67	87	81
#2-People have time, space, and opportunity for privacy	87	75	84	87	89	83	91	86	100	100	83	93	86
#3-People decide when to share personal information	87	77	88	89	90	94	97	93	89	75	67	90	88
#4-People use their environments	75	60	72	78	84	64	81	79	100	88	83	82	76
Mean	82	69	81	85	88	82	87	85	97	84	75	88	

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54

**PERCENT OF AFFILIATION OUTCOMES ACHIEVED BY PEOPLE WITH DIFFERENT PRIMARY DISABILITIES UP
TO 1998**

PRIMARY DISABILITY

	<i>Other</i>		<i>Profound MR</i>		<i>Severe MR</i>		<i>Moderate MR</i>		<i>Mild MR</i>		<i>CP</i>	<i>Autism</i>	<i>Seizure</i>	<i>Hearing</i>	<i>Vision</i>	<i>TBI</i>	<i>MI</i>	<i>Mean</i>
AFFILIATION	#1-People live in integrated environments		32	6	10	22	42	30	19	34	33	13	50	38	26			
	#2-People participate in the life of the community		85	65	82	90	92	78	95	90	100	75	67	88	85			
	#3-People interact with other members of the community		67	87	54	71	77	73	71	86	100	63	83	67	65			
	#4-People perform different social roles		43	12	21	24	40	48	48	41	56	25	67	27	31			
	#5-People have friends		59	42	56	66	70	64	55	76	67	75	83	59	61			
	#6-People are respected		72	53	66	72	82	81	86	79	100	50	50	76	72			
Mean			60	36	48	57	67	63	67	68	65	50	67	60				

PERCENT OF ATTAINMENT OUTCOMES ACHIEVED BY PEOPLE WITH DIFFERENT PRIMARY DISABILITIES UP
TO 1998

PRIMARY DISABILITY														
	Other	Profound MR	Severe MR	Moderate MR	Mild MR	CP	Autism	Seizure	Hearing	Vision	TBI	MI	Mean	
ATTAINMENT	#1-People realize personal goals	87	83	75	86	89	84	86	76	78	75	100	86	85
	#2-People choose services	48	29	35	42	55	64	71	52	44	25	67	37	44
	Mean	67	56	55	64	72	74	78	64	67	50	83	61	

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NUMBER OF RIGHTS OUTCOMES FOR PEOPLE WITH DIFFERENT PRIMARY DISABILITIES UP TO 1998

PRIMARY DISABILITY														
	Other	Profound MR	Severe MR	Moderate MR	Mild MR	CP	Autism	Seizure	Hearing	Vision	TBI	MI	Mean	
RIGHTS	#1-People exercise rights	37	17	20	18	33	54	29	45	25	13	50	24	27
	#2-People are treated fairly	49	27	32	30	43	64	34	55	50	13	50	29	37
	Mean	43	38	26	26	38	59	32	50	38	13	50	27	

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NUMBER OF HEALTH OUTCOMES FOR PEOPLE WITH DIFFERENT PRIMARY DISABILITIES UP TO 1998

PRIMARY DISABILITY													
	Other	Profound MR	Severe MR	Moderate MR	Mild MR	CP	Autism	Seizure	Hearing	Vision	TBI	MI	Mean
HEALTH	#1-People have the best possible health	72	54	73	70	77	85	76	100	50	67	62	70
	#2-People are free from abuse and neglect	89	88	83	88	83	86	89	89	100	100	86	87
	#3-People experience continuity and security	85	93	89	88	92	89	97	100	100	83	84	89
	Mean	56	80	82	81	83	83	89	86	96	83	83	78

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NUMBER OF SAFEGUARDS OUTCOMES FOR PEOPLE WITH DIFFERENT PRIMARY DISABILITIES UP TO 1998

		PRIMARY DISABILITY												Mean
		Other	Profound MR	Severe MR	Moderate MR	Mild MR	CP	Autism	Seizure	Hearing	Vision	TBI	MI	
SAFEGUARDS	#1-People remain connected to natural support networks	70	65	68	70	80	87	78	72	75	88	83	71	72
	#2-People are safe	92	89	93	89	84	88	96	90	88	75	67	86	89
	Mean	80	77	80	80	82	88	83	81	81	81	75	79	

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PERCENT OF IDENTITY OUTCOMES ACHIEVED BY AGE GROUP UP TO 1998

		AGE GROUP				Mean
		LESS THAN 6	6 - 18	19 - 65	OVER 65	
IDENTITY	#1-People choose personal goals	73	57	35	28	35
	#2-People choose where and with whom they live	96	66	43	35	44
	#3-People choose where they work	93	80	30	44	35
	#4-People have intimate relationships	96	86	67	63	67
	#5-People are satisfied with services	100	89	86	73	86
	#6-People are satisfied with their personal life situations	95	82	82	82	83
Mean		90	77	57	57	

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PERCENT OF AUTONOMY OUTCOMES ACHIEVED BY AGE GROUP - 1998

		AGE GROUP				
		LESS THAN 6	6 - 18	19 - 65	OVER 65	Mean
AUTONOMY	#1-People choose their daily routine	98	87	81	68	81
	#2-People have time, space, and opportunity for privacy	98	81	86	87	86
	#3-People decide when to share personal information	96	96	87	85	88
	#4-People use their environments	92	77	77	67	77
Mean		92	85	83	77	

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PERCENT OF AFFILIATION OUTCOMES ACHIEVED BY AGE GROUP UP TO 1998

	AGE GROUP				Mean
	LESS THAN 6	6 - 18	19 - 65	OVER 65	
AFFILIATION					
#1-People live in integrated envioronments	84	24	25	21	27
#2-People participate in the life of the community	98	90	85	75	86
#3-People interact with other members of the community	91	66	65	62	66
#4-People perform social roles	91	38	28	31	30
#5-People have friends	82	55	61	59	61
#6-People are respected	96	81	71	64	72
Mean	88	60	56	52	

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PERCENT OF ATTAINMENT OUTCOMES ACHIEVED BY AGE GROUP UP TO 1998

		AGE GROUP				
		LESS THAN 6	6 - 18	19 - 65	OVER 65	Mean
ATTAINMENT	#1-People choose services	78	61	43	39	45
	#2-People realize personal goals	89	93	83	81	84
Mean		83	77	54	60	

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PERCENT OF RIGHTS OUTCOMES ACHIEVED BY AGE GROUP UP TO 1998

	AGE GROUP				<i>Mean</i>
	<i>LESS THAN 6</i>	<i>6 - 18</i>	<i>19 - 65</i>	<i>OVER 65</i>	
RIGHTS #1-People exercise rights	80	43	23	24	26
#2-People are treated fairly	87	53	34	32	37
Mean	83	48	29	28	

PERCENT OF HEALTH OUTCOMES ACHIEVED BY AGE GROUP UP TO 1998

		AGE GROUP				Mean
		LESS THAN 6	6 - 18	19 - 65	OVER 65	
HEALTH	#1-People have the best possible health	76	77	70	60	70
	#2-People are free from abuse and neglect	89	82	86	94	87
	#3-People experience continuity and security	82	88	90	93	90
	Mean	83	83	80	82	

PERCENT OF SAFEGUARDS OUTCOMES ACHIEVED BY AGE GROUP UP TO 1998

		AGE GROUP				Mean
		LESS THAN 6	6 - 18	19 - 65	OVER 65	
SAFEGUARDS	#1-People are conected to natural support networks	91	77	73	65	73
	#2-People are safe	92	92	88	81	88
	Mean	92	84	81	73	

**PERCENT OF IDENTITY OUTCOMES ACHIEVED IN DIFFERENT SIZE
ORGANIZATIONS UP TO 1998**

	SIZE OF ORGANIZATION						Mean
	< 25	26- 50	51- 100	101- 200	201- 500	> 500	
IDENTITY							
<i>#1-People choose personal goals</i>	38	33	39	44	37	26	37
<i>#2-People choose where and with whom they live</i>	51	59	47	50	41	34	46
<i>#3-People choose where they work</i>	31	41	38	41	33	25	36
<i>#4-People have intimate relationships</i>	60	63	71	74	82	59	70
<i>#5-People are satisfied with services</i>	80	89	88	88	84	83	86
<i>#6-People are satisfied with their life situations</i>	78	85	83	86	81	75	82
Mean	56	62	61	64	36	50	

**PERCENT OF AUTONOMY OUTCOMES ACHIEVED IN DIFFERENT SIZE
ORGANIZATIONS UP TO 1998**

		SIZE OF ORGANIZATION						Mean
		< 25	26- 50	51- 100	101- 200	201- 500	> 500	
AUTONOMY	#1-People choose their daily routine	85	91	85	82	81	57	81
	#2-People have time, space, and opportunity for privacy	89	81	86	89	88	64	85
	#3-People decide when to share personal information	86	82	91	92	93	79	88
	#4-People use their environments	82	78	79	78	78	54	76
Mean		85	83	85	85	85	63	

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**PERCENT OF AFFILIATION OUTCOMES ACHIEVED IN DIFFERENT SIZE
ORGANIZATIONS UP TO 1998**

	SIZE OF ORGANIZATION						Mean
	< 25	26- 50	51- 100	101- 200	201- 500	> 500	
AFFILIATION							
<i>#1-People live in integrated environments</i>	28	23	26	24	25	20	25
<i>#2-People participate in the life of the community</i>	89	92	93	88	83	64	85
<i>#3-People interact with other members of the community</i>	71	71	71	71	55	41	65
<i>#4-People perform social roles</i>	37	34	34	36	32	18	31
<i>#5-People have friends</i>	45	68	63	61	66	58	62
<i>#6-People are respected</i>	80	75	72	78	67	62	72
Mean	58	60	60	60	54	44	

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**PERCENT OF ATTAINMENT OUTCOMES ACHIEVED IN DIFFERENT SIZE
ORGANIZATIONS UP TO 1998**

		SIZE OF ORGANIZATION						Mean
		< 25	26- 50	51- 100	101- 200	201- 500	> 500	
ATTAINMENT	#1-People choose services	52	56	53	54	42	30	48
	#2-People realize personal goals	86	87	94	87	78	78	85
Mean		69	72	73	70	60	54	

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**PERCENT OF RIGHTS OUTCOMES ACHIEVED IN DIFFERENT SIZE
ORGANIZATIONS UP TO 1998**

Count

		SIZE OF ORGANIZATION						Mean
		< 25	26-50	51-100	101-200	201-500	> 500	
RIGHTS	#1-People exercise rights	31	54	31	35	29	17	28
	#2-People are treated fairly	42	34	32	48	48	27	41
	Mean	36	26	32	42	39	22	

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**PERCENT OF HEALTH OUTCOMES ACHIEVED IN DIFFERENT SIZE
ORGANIZATIONS UP TO 1998**

		SIZE OF ORGANIZATION						Mean
		< 25	26- 50	51- 100	101- 200	201- 500	> 500	
HEALTH	#1-People have the best possible health	68	67	74	77	74	56	71
	#2-People are free from abuse and neglect	80	86	77	89	90	86	86
	#3-People experience continuity and security	86	87	88	91	90	90	85
Mean		78	80	80	86	85	78	

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**PERCENT OF SAFEGUARDS OUTCOMES ACHIEVED IN DIFFERENT SIZE
ORGANIZATIONS UP TO 1998**

		SIZE OF ORGANIZATION						Mean
		< 25	26- 50	51- 100	101- 200	201- 500	> 500	
SAFEGUARDS	#1-People are connected to natural support networks	66	77	72	75	78	66	74
	#2-People are safe	89	86	88	89	92	83	89
	Mean	78	82	80	82	85	74	

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CONCLUSIONS

Individual with disabilities are consumers who are entitled to the best quality of life and optimal outcomes that organizations, communities, and government entities should be expected to provide. Individuals with disabilities and their families, as well as taxpayers in general, should expect the best and be aware of service and/or support characteristics which lead to the best possible outcomes. Using the analytic technique of data mining, we have explored The Council's personal outcomes database and have examined organizational characteristics which are associated with outcomes for individuals with disabilities.

With respect to The Council's outcomes model, such expectations are also coupled with an intention to use the *Personal Outcome Measures* for:

- Learning – to learn about people receiving services and supports. Organizations should discover the person's own meaning for each of the 25 *Personal Outcome Measures*.
- Facilitating – Once an organization entity has learned a person's definition of the outcomes, it then organizes resources and coordinates the services and supports that facilitate these outcomes. Sometimes organizations and teams have to try several different ways to facilitate an outcome. Learning from different approaches often leads to the most practical mixture of supports and services for facilitating an outcome.
- Measuring – After an organization aligns services and supports to facilitate personal outcomes, it determines if the person has achieved the outcome as he or she has defined it. The organization then aggregates the individual determinations to form a picture of how well it (the organization) is performing. The evaluation can serve formative or summative purposes. The evaluation can be an internal self-assessment or it can be performed by an independent third party evaluator.

The development and use of valid and reliable outcomes measures -- such as the *Personal Outcome Measures* -- lies at the intersection of the paradigms of policy devolution, program accountability, disability research, and independent living. Local communities should have access to outcomes models that can be easily applied, analyzed, and understood. Taxpayers should expect that government funded programs, services and supports create results - - e.g., satisfaction with services and supports, organizational efficiency and effectiveness. People with disabilities should expect that they will be active players in the outcomes data collection and research conducted on their behalf. And all people should expect that outcome data collection and research models incorporate measures related to choicemaking, satisfaction, control over resources, and lifestyle changes that reflect the true nature of a person's full quality of life.

What other databases currently exist that can meet this country's needs for accurate and reliable outcomes information? As part of its mission, The National Center on Outcomes Research (NCOR) will continue to identify, mine, analyze, and present outcomes data and trends from other reputable databases. NCOR will conduct future data mining efforts with: (a) the National Health Interview Survey - Disability Supplement of 1995, and (b) the Harris/NOD Disability Survey of 1998, to name just a few.



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